



21ST CENTURY VISION

A Discussion Paper in association with the
Housing and Support Alliance

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SUMMARY

The launch of the Housing and Support Alliance coincides with a moment of great crisis in the history of people with learning difficulties. Decades of slow progress away from institutional provision and towards full citizenship are in danger of being reversed by cuts that target disabled people, by the use of appalling rhetoric by the press and government, and also by the corruption of the very innovations that had promised to transform past practice.

This paper argues:

- We need to develop new vision for the 21st century, one that is rooted in the knowledge that institutions do not need walls, and one that is prepared to look honestly at our past history and our current reality.
- We need to define and support full citizenship, in all its aspects, and this will mean moving beyond the restricted models and solutions provided by many community services. It means being citizens and supporting each other as citizens.
- We have tried to help people move into full and meaningful lives but we have found ourselves trapped by our own thinking. We continue to think within a closed off world of special jargon, systems and models. Rather than really changing the system we have found that the system has adopted and then corrupted our best ideas.
- The current economic and political crisis was not created by disabled people, and yet the scapegoating of disabled people has been one of its central features; this must strip away any illusion that we have protected people from abuse.
- We must challenge ourselves to move forward with our eyes open. We need to abandon the special jargon and the formulaic approaches to change. Instead we need to get more practical, more political and more in tune with our times and the interests of ordinary people.

It is possible for us to develop a new, 21st century vision, but that vision must no longer be a special vision, for a special people, instead it must be our vision, for each other.

INTRODUCTION

The following paper is based on the talk that I gave at the launch conference for the Housing and Support Alliance (H&SA) in 2012. This paper is not really the talk that I actually gave (the real talk was, thankfully, much shorter) but this paper does outline the thinking that underpinned that talk.

My basic observation is that we have arrived at a moment of crisis, and that everything we do from now on will depend upon how we picture the future we want, and whether we decide to work towards that vision. We can no longer take it for granted that things will 'only get better' - for they are in grave danger of getting very much worse.

At times like this we don't need grand new theories or ideologies. Instead we need to go back to basics. We need to start thinking and talking in ways that ordinary people can understand. We need to get political, resist bad policies and propose better policies. We need to get organised, build alliances and form coalitions. We need to support each other and to share everything we've learned.

For those who are prepared to act, to defend the rights of people with learning difficulties, and to challenge injustice, then we must learn the lessons of our history. We can make progress, but it will not happen by just waiting for better times to arrive. Any new vision must begin by looking honestly at our current reality. We can stop things getting worse, we may even be able to make them better, but only if we can keep our eyes open and look truthfully at what is really going on.

1. TIME FOR NEW VISION

We need to develop new vision for the 21st century, one that is rooted in the knowledge that institutions do not need walls, and one that is prepared to look honestly at our past history and our present reality.

It's an honour to speak at this - the launch conference for the *Housing and Support Alliance* (H&SA). It's always exciting when new life begins - especially when it is brought into being by the coming together of two organisations that have already played a positive role in advancing the rights of people with learning difficulties: *Housing Options* and the *Association for Supported Living*.

And what a moment.

Never before have we seen such a direct attack on the rights and interests of disabled people. Never before have we seen radical cuts to social care. Never before have we seen such an increase in central government power. Never before have we seen such direct efforts to undermine human rights, the duties of citizens and the role of government in guaranteeing our basic securities.

We have moved, from a period of slow and incremental progress, to a new period where all bets are off. If social care can be cut by 33% by 2015, then why not cut it by 50% by 2018? If the UK is the third most unequal developed country in 2012, then why can we not be more unequal than the USA by 2020? If we already fail to meet the standards of the *UN Declaration of Human Rights* and the *UN Convention of the Rights of Persons with Disabilities*, then perhaps we will soon see human rights declared irrelevant - just another obstacle to be overcome.

But an obstacle to what? What kind of society are we trying to create? And what kind of society should we be trying to create?

I offered to talk about how we can develop vision for the 21st century and the term 'vision' here has at least two different meanings. We certainly need to think about the kind of *future* we want and we need to develop a vision for the future, one that respects the perspective and values of many different people. However we also need to see things now - to develop our *capacity* for vision - our ability to **see** where we have been, where we are now and what opportunities and risks lie ahead.

I suspect that this is the greater challenge. I do not think we will disagree much about where we need to go. However I do not think we really share a vision of where we are now and of the challenges that lie immediately ahead. I think that our capacity for vision has been very limited and that we are not

well prepared to confront the full reality of our situation.

We can begin by looking backwards. It is impossible to talk about the history of people with learning difficulties without referring to the institutions. One of our achievements has been that, today, the long-stay institutions, are now closed. However, one of our current failings is that, today, 11,000 people with learning difficulties are living in new **private institutions**. In fact it looks like we are spending about the same money that we used to spend on the institutions on about one sixth of the people.

This failure to include everybody in the process of de-institutionalisation, has not been our only failure. Largely we replaced large institutions with smaller institutions: groups homes, care homes, hostels, day centres, sheltered workshops, residential respite units, residential colleges and special units. We also did this in a way which largely robbed people of choice and control. Instead, people have had to simply accept whatever was commissioned for them (see Figure 1).

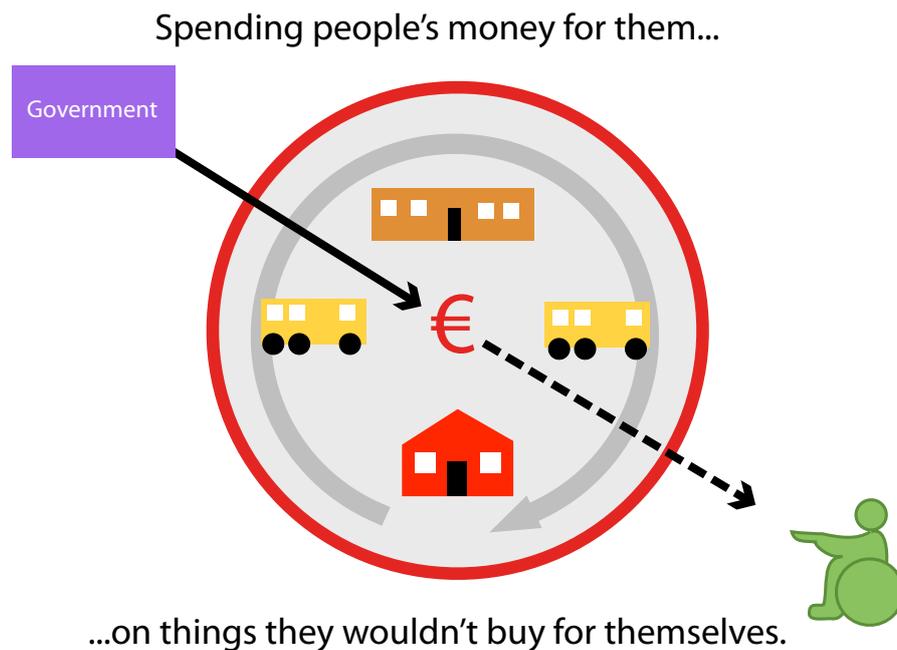


Figure 1. Spending people's money on things they wouldn't buy for themselves

This failure was rooted in an even deeper failure. For we did not really think hard enough about what was *wrong* with the institutions in the first place. Too often we focused on the size and location of the institution - as if the problem was that lots of people with learning difficulties were living together in the countryside. But that was never the real problem.

It is not walls that make an institution. Institutions are human systems of control that are organised to:

- 1. Devalue human life** - remove our unique sense of purpose, and instead replace it with goals that are defined by our 'grade' or our place within the system.
- 2. Remove freedom** - deny us control over our own destiny, take away our ability to choose and our capacity to shape our own life around our own needs and aspirations.
- 3. Ensure poverty** - strip away our property rights, reduce economic power, and replace independence with demeaning dependence on the system.
- 4. Guarantee homelessness** - perhaps provide us with a roof, but with no rights, no privacy, no sense of belonging.
- 5. Provide care, but no support** - but instead treat us as passive objects who have no ability to set our own goals, to learn, to develop or create.
- 6. Isolate us** - to make it harder for us to join in, make a difference, and enjoy all that community life can offer.
- 7. Make love difficult** - impose upon us a life of sterility and loneliness, lost to family, friends and the wider community.

It is important to see that the threat of the institution remains, whether or not we use camps, long-stay hospitals or asylums. The institution is not a place, it is a way of thinking and being, and it is a constant threat to human dignity. And it is not just a threat to people with learning difficulties. In fact, if we really understand what is wrong with the institution, then we will also see that it is a threat to **all of us** - at every stage of our lives.

We can all be institutionalised, without even noticing. We can all slip into living empty lives where we let others dictate how we live and the meaning of our life. We can all become dependent and focused on mere survival within the system. We can all measure ourselves by the empty and narrow standards that are offered by society in place of real values.

A new vision must be our vision. Not a vision for other people - people with learning difficulties - but a vision for everyone and, especially, **a vision for ourselves.**

2. SEEING OURSELVES AS CITIZENS

We need to define and support full citizenship, in all its aspects, and this will mean moving beyond the restricted models and solutions provided by many community services. It means being citizens and supporting each other as citizens.

Without a doubt, the lives of many people with learning difficulties are now much better than they once were. But many of us know that too many community services remain deeply institutional. For many people their whole life is defined by their relationship with services. There is too little flexibility and too little opportunity to exercise our basic human rights. For many people the shift to community services was the equivalent of moving to a new institution - but one without a park.

In fact, we find that the failure to end the use of institutions, and a growing dependence on private institutions, has also been partially caused by the limitations of those community institutions. It turns out that if you fail to offer people flexible, personalised support, if you control people and do not support their full development, if you stop people from having relationships of meaning and love, then some people will get angry and rebel. And so placements (a horrible, but revealing, word) breakdown and people are then shifted further and further away from their homes and communities.

I recently came across a starkly honest perspective on the root cause of the institutional response of the health and social care system, by the psychiatrist R D Laing:

It is not easy. What do we do when we don't know what to do? I want that guy out of sight, out of sound, out of mind... The situation keeps cropping up in our society, when no matter how liked, esteemed or loved, some people become insufferable to others. No one they know wants to live with them. They are not breaking the law, but they arouse in those around them such urgent feelings of pity, worry, fear, disgust, anger, exasperation, concern, that something has to be done. A social worker or psychiatrist is 'brought in'.

And so, when psychiatrists and social workers find they also don't have a solution then we send people to the institution.

However we do not need to be caught in an endless cycle, repeating these old mistakes. There is a way out of the trap.

Many individuals and organisations - often led by disabled people or their families - have created radical new innovations that open up new possibilities.

Some of the innovations that have had the most positive impact for people with learning difficulties include:

- **Family leadership** - putting families in the driving seat as they bring up disabled children to be full citizens.
- **Inclusive education** - families and children exercising their right to an education alongside their peers in the mainstream.
- **Supported employment** - support to find and keep ordinary jobs with proper salaries.
- **Supported living** - support and housing separated to help secure full housing rights and choice of support.
- **Person-centred planning** - creative thinking and planning led by people themselves and those they love.
- **Shared lives** - people living together as friends or colleagues.
- **Personalised support** - flexible support designed around your needs and lifestyle.
- **Individual budgets** - an entitlement to flexible funding that you can control.
- **Self-advocacy** - people speaking up for themselves and for each other.

These are not the only important innovations, and other groups, like people with physical disabilities have developed other important innovations to achieve independent living, like personal assistants, direct payments, and centres for independent living (see Figure 2).

It is also worth noticing that these practical innovations do not seem to emerge 'on their own'. These practical innovations often seem to be a creative response to ideas and theories that have offered a different way of thinking about disability and disadvantage:

- **Social model of disability** - recognising that disability and disadvantage arises because of the failure of society to adapt to the different needs of disabled people
- **Social role valorisation** - recognising that disadvantage is reinforced by stigma and the damaging stereotypes that can be thoughtlessly reinforced by services and by society

- **Disability rights** - recognising that justice demands that we respect human rights, and that those rights must respect the full range of human diversity
- **Inclusion** - cherishing human diversity and the relationships and mutual benefits that flow from a society that can welcome and support difference.

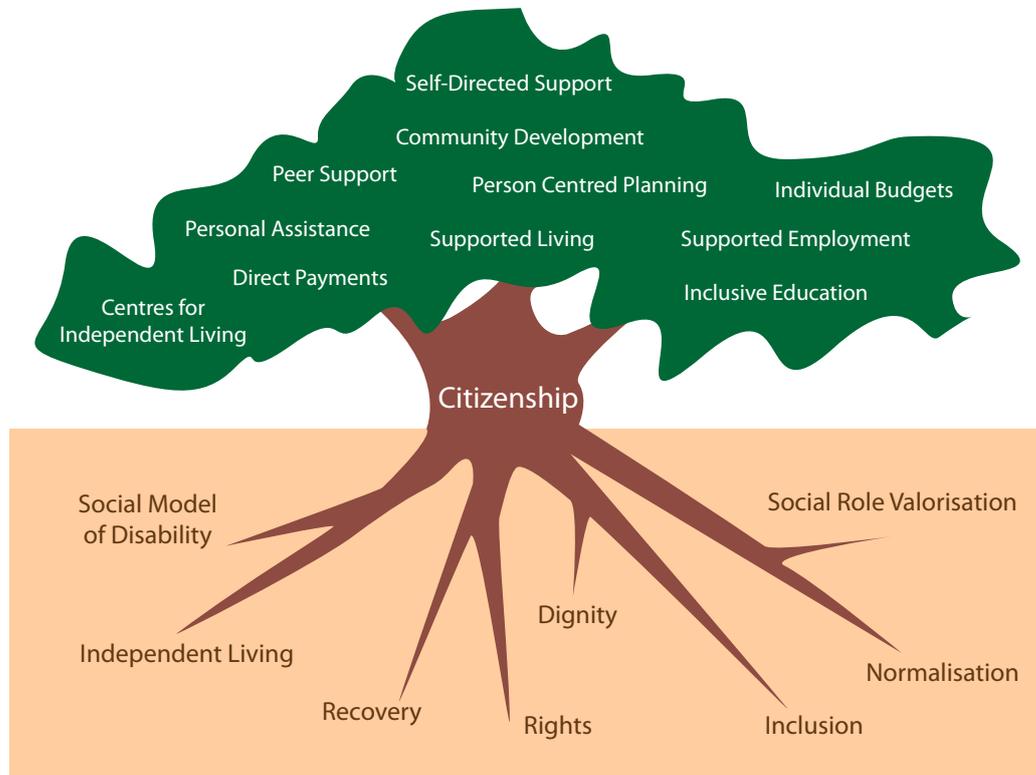


Figure 2. Social innovations and their roots

Each of these theories has their own strengths and weaknesses, but I would argue that they all share a common faith in the full **citizenship** of all disabled people - in fact **all people** who are disadvantaged by birth, accident or stigma. This citizenship may not always be recognised or supported by society - but it is a **real moral fact** - and it is our job to make this citizenship real even when society fails to recognise it.

In fact, if we try to understand how citizenship is actually achieved then we find can identify a range of practical elements, each of which is essential to full citizenship. If we are citizens then our lives have:

1. **Purpose** - we live a life of meaning
2. **Freedom** - we direct our own lives
3. **Money** - we have enough to build on without undue dependence
4. **Home** - we are where we belong and with people who matter

5. **Help** - we get support that fits who we are and helps us achieve our goals
6. **Life** - we can get stuck in and contribute to our communities
7. **Love** - we can get love and give love, in all its forms

This is not about narrow human service ideologies, it is about basic moral and political values.

John O'Brien, one of the thinkers who has been most helpful on our journey, someone who has avoided the promotion of any simplistic ideology, describes citizenship like this:

Citizens are people who can say "I belong to this place and it's people and I am willing to act from responsibility for my belonging." People with disabilities are among those who are vulnerable to social exclusion: being pushed to the edges of society and deprived of what they require to participate actively. Citizenship creates a framework for understanding what it is that we're really trying to do when we become allies with people with disabilities who are seeking a life that makes sense.

This is not just a call for some special people - 'service people' - to be better at treating other people as citizens. It is a call that **all of us to see ourselves as citizens**. We must not fall into the trap of seeing ourselves as mere functionaries, as people who are just doing 'a job'.

For, as Winston Churchill puts it:

We make a living by what we get; we make a life by what we give.

This way of thinking - **citizenship thinking** - must be at the heart of any new vision for the 21st century. And one of its great strengths as an approach is that it is not insular. It is not a special theory which just makes sense for some special group. It is a mainstream theory, and one with much wider applicability. If we were to take it seriously it would not just change what we do - it would change who we are.

3. THINKING FROM WITHIN THE BOX

We have tried to help people move into full and meaningful lives but we have found ourselves trapped by our own thinking. We continue to think within a closed off world of special jargon, systems and models. Rather than really changing the system we have found that the system can adopt and then corrupt our best ideas.

One of the reasons that it is so difficult to accept that things are now going so badly wrong is that for many years many of us have really felt that we were making some kind of progress.

You can picture this progress as a journey by which we have slowly tried to tackle and overcome three different kinds of institutional response to human diversity:

1. **The walled institution** - the long-stay hospital, the asylum or the special unit which utterly excludes the individual from ordinary life.
2. **Community services** - that restrict the person's life by the use of defined and funded placements, services and models of care and support.
3. **The welfare system** - that enmeshes people in poverty and systems of regulation and control - undermining dignity, freedom and human development.

For people with learning difficulties progress has been limited, but it has been real. There are now many people at every stage of this journey. The big institutions are closed, but far too many people are trapped in institutions (including our prisons and assessment and treatment units). Many people are far too many are dependent upon unnecessarily institutional services provided by community services. Far too few people really get the chance to enjoy lives of full and equal citizenship. Yet many do, and they demonstrate quite clearly that people with learning difficulties are not just citizens - they are often super-citizens: the most active, supportive and creative people in the local community (see Figure 3).

As we have gone on this halting journey towards citizenship we also find that the landscape changes and that some of the challenges we faced in the past are not identical to the challenges we face today.

It is sometimes very hard to see that the way in which we resolve problems also needs to evolve as the problems themselves evolve.

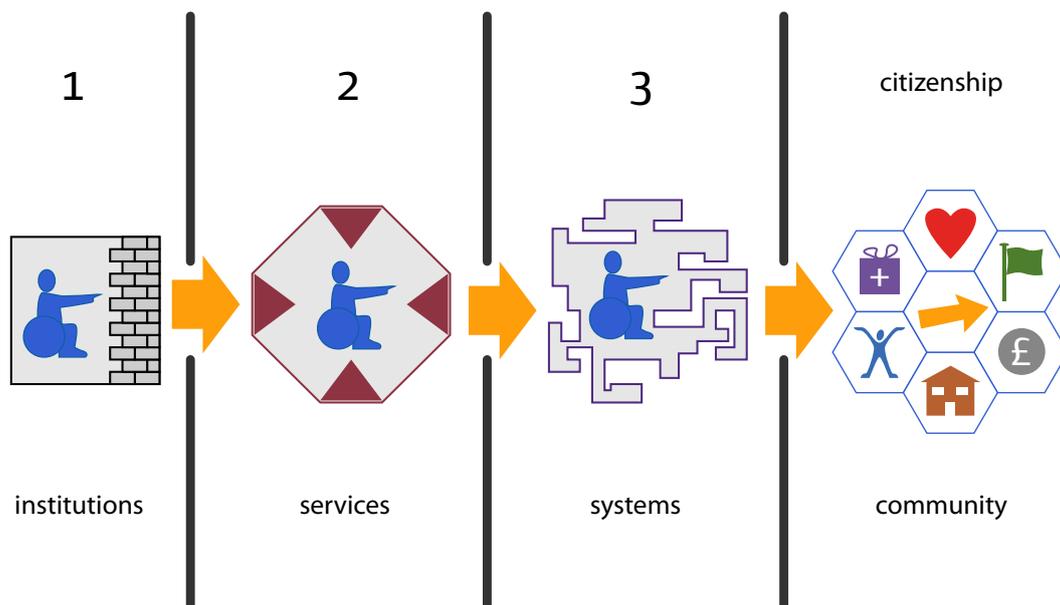


Figure 3. The journey towards citizenship

Initially, when our goal was to get people out of walled institutions, it was natural to define solutions in ways that mirrored that problem. We created a new theory - normalisation or social role valorisation - which was developed to expose the flaws of the institution. We created new models of care and new funding systems. New professions, new groups, new campaigns were organised around the task of moving people out and supporting people in communities: service providers, housing consortia, community teams, learning disability nurses and so forth.

The strength of this approach is that it was direct, effective and simple. The weakness of this approach is that it has led to the development of a new kind of institution: special people, served by special professionals, using a special theory, in a special and peculiar service world. A special community which somehow exists both inside and outside ordinary community life at the same time - like some strange space-time anomaly. Interestingly, even as we tried to devise alternatives to the special world of community services, so we also tended to adapt our thinking and solutions to this strange world:

- Getting a job became 'supported employment'
- Getting a home became 'supported living'
- Getting friends became 'community building'

- Getting a life became ‘person-centred planning’
- Getting real entitlements became ‘self-directed support’
- Working together became ‘coproduction’

Jargon, models and special systems are the currency of the special world. We did not use common sense, basic decency or human rights as our framework. Instead we wrapped people in our new and improved technologies and systems. Moreover we were always surprised when, after some early successes, the ideas that we had developed were then reabsorbed by the system and reduced to a handful dust - failing to achieve the desired outcomes or sometimes making things even worse.

I make these remarks as someone who has a track-record of contributing to this problem and in the sure knowledge that my own view will seem too extreme and too negative. However I feel that unless we are honest about the limitation of this jargonised approach then we will be doomed to constant disappointment and to a fearful waste of energy and good will.

Here are three examples of really good ideas that have now been corrupted to the point when it is, at least, an open question as to whether they are doing more harm than good. For it can be argued that each of these ideas becomes harmful when it offers a distracting substitute in place of the real change that is required - a stone instead of bread [Matthew 7.9].

- 1. Person-centred planning** - once a powerful approach for shifting power to individuals and families, asserting their dignity and their own sense of purpose. Too often it becomes a sterile exercise in “pyramid-selling” by consultancy firms who offer placebos in place of real change. One mother told me recently how she received a ‘one page profile’ of her own daughter from a Speech and Language Therapist. This is the last thing that the inventors of person-centred planning intended.
- 2. Supported living** - once a helpful framework for affirming the basic human rights of disabled people and for challenging the norm of group living that had been imposed on people with learning difficulties. I recently attended a national conference on supported living where I was shocked to discover that the concepts that I’d been part of been defining in 1992 had now been completely forgotten. Supported living has now come to mean group living - exactly very concept it was designed to challenge.
- 3. Self-directed support** - is a recent effort to reform the system of funding for services and to create a system of entitlements under the control of disabled people. Unfortunately this approach has now been stood on its head. Bogus systems of assessment and resource allocation and

patronising systems of support planning only serve to disguise the system's on-going failure to give people meaningful entitlements that they can control. Many people find, when they finally get to the end of this unduly complex process, that they are punished for creativity as panels of managers unpick their support plans.

How did we get here? Somehow we have crossed over to the other side of the looking glass.

Perhaps part of the problem is that we have simply been thinking within a box - the special box of special services. These ideas are not developed as part of mainstream society, they are developed as special innovations within the special world that they are trying to change. As such they actually perpetuate the problem that they are trying to tackle.

Initially, when these ideas are developed and sustained by a dissonant community within that world, that community can define and protect those ideas. However, when the ideas begin to be treated as valuable by the wider system then they become highly corruptible. They are then turned into something that the wider system finds easier to adopt: a planning process, some new paperwork, a new job role, new jargon for the business plan or even just a new name for an old practice.

In a sense the system first takes ownership of the innovation and then declares victory at its own convenience - simply translating the innovation into something that is easy for it to achieve. The innovation remains under-developed, and over time it becomes increasingly toxic as it undermines more genuine efforts to bring about change. It has served to inoculate the system from meaningful change - 'Oh we've done person-centred planning - we've got full accreditation.'

Innovations in public services rarely succeed because the system simply adopts them without really using and absorbing them. Real innovations must undergo real life testing, development, competition and challenge. Real innovations have to really work; they have to be valued and they have to become necessary only by reason of their effectiveness. A real innovations cannot simply be redefined by government to mean the opposite of what it used to mean (see Figure 4).

Our jargonised innovations did do some work; they did prove that positive change was possible. But they are have largely been corrupted by a system that does not want to change and which has the power to control and redefine any innovation which threatens the status quo.

We have reached a point where we must radically re-evaluate our fundamental strategy for bringing about positive change. We have tried to introduce positive, radical and transformational reforms **from within the**

box. We have operated, not as citizens, but as special technicians trying to tweak the system. But, in the end, the system just tweaks us back.

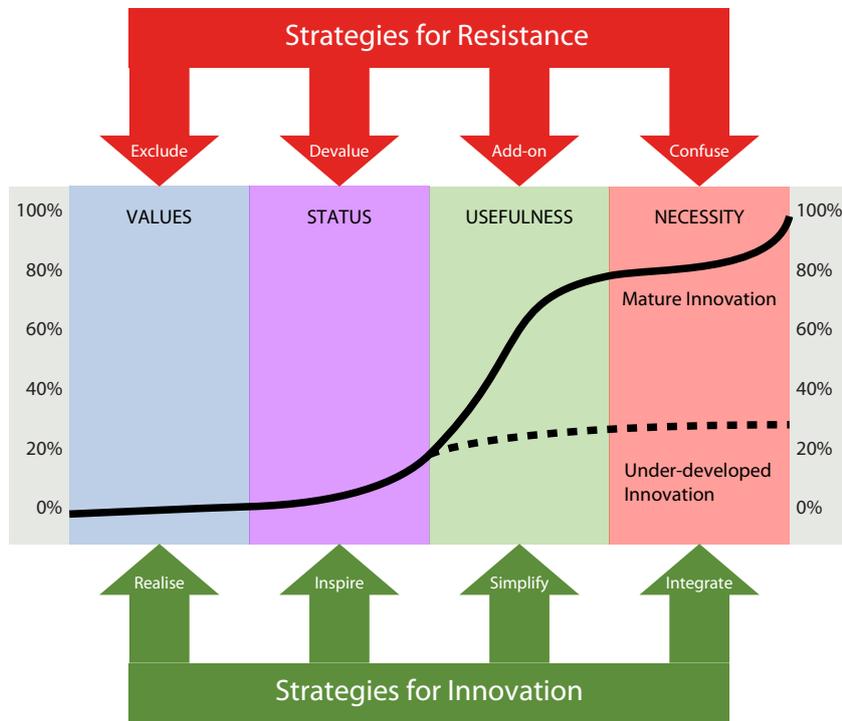


Figure 4. The corruption of innovations

And, while all of this is going on, the world moves on. While we have been battling to create, implement, protect or exploit our latest piece of jargon we have failed to see the very real threats that are emerging and which are growing to engulf us.

4. WAKING UP TO THE CRISIS

The current economic and political crisis was not created by disabled people, and yet the scapegoating of disabled people has been one of its central features; this should strip away any illusion that we have protected people from abuse.

One of the central tenet of those leading the process of de-institutionalisation from the 1970s onwards was ‘never again’. We hoped that our efforts could put the stigmatised past behind us, and that we could protect people from abuse by ensuring that service solutions were ‘normalised’. People were to be visible and valued members of society, not scapegoated and excluded. Much was achieved. But the limits of those achievements have never been so obvious.

In 2010 the in-coming coalition government in the UK announced the deepest cuts in public expenditure and the most extreme programme of ‘reforms’ since World War II. Party dogma and ideology have certainly played some part in the development of these policies. But we must also notice that these policies are highly consistent with the thread of policies developed by the previous government.

Percentage growth or cut in annual funding by 2015 in real terms

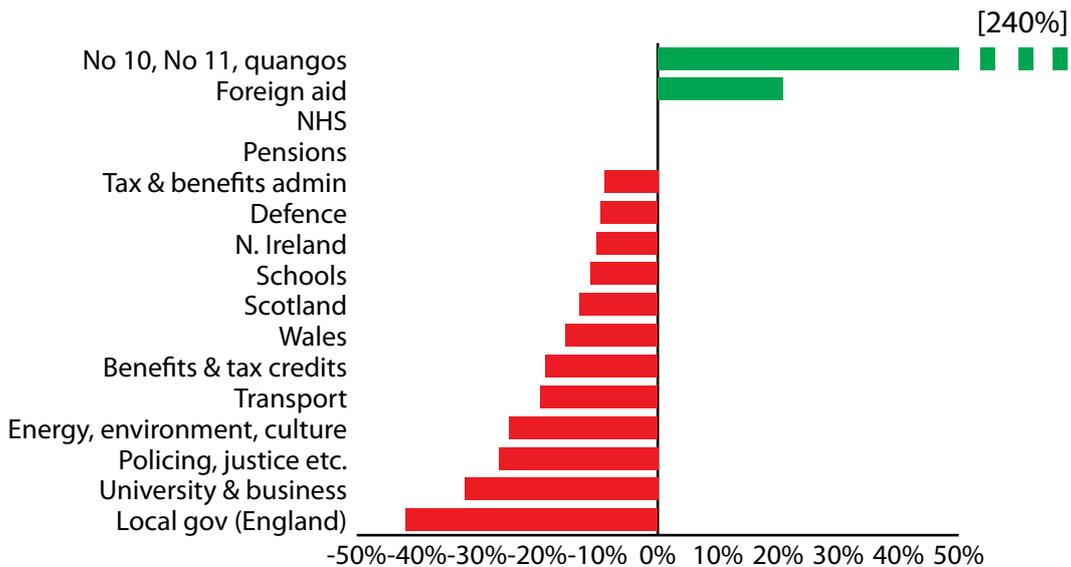


Figure 5. Percentage cuts in UK real term funding (2010-15)

It is not possible to do justice to the full range of these policies here, but in outline it is possible to identify several key changes:

- **Deep cuts in social care** - In England it is likely that social care for children and adults will be reduced by 33% by 2015. In the last two years £2 billion has already been cut from adult social care alone and there is much more to come. These deep cuts stand in contrast to modest growth in the NHS and pensions (see Figure 5).
- **Cuts in disability incomes** - A range of interconnected cuts in benefits will drive disabled people into deeper levels of poverty: increased social care charges, reduced levels of income security, replacement of DLA with PIP, changes to the indexation of benefits which will reduce their value over time.
- **Cuts to housing** - Changes in Housing Benefit levels and their associated regulations, reductions in the value of Mortgage Income Relief and reduced funding for housing developments will all make it more difficult for people to live in homes of their own or with family and friends. The pressure for re-institutionalisation will grow.
- **Stigmatisation** - Shockingly, government ministers and civil servants seem to have adopted rhetoric devices that directly stigmatise the poor and disabled people. There seems to be a purposeful effort to represent disabled people as fraudsters, scroungers, lazy and unproductive. Positive rhetoric is primarily focused on the 'middle' or swing voter groups who are represented as being 'burdened' or 'squeezed' by the poor.
- **Hate crime and abuse** - Unsurprisingly, when government leads the charge against disabled people, we find that many ordinary people follow. Hate crime has increased and it is likely that institutional abuse - already a major problem - will also increase, as staff are encouraged to see those they support through the distorted lens of government rhetoric.

I am not sure that many of us have woken up to what is really happening. I suspect that many think that if things were really this bad then surely the Labour Party would have made more fuss. I suspect that many think that if any of this was really happening then surely the media would be having a field day. I suspect that many of us think that our leaders and their officials, who can all seem so reasonable and so well intentioned, would not really be doing these things. But we need to wake up and open our eyes.

These things are happening and nothing is going to inevitably stop them from happening. The forces that have created this crisis, and which are driving the current agenda, are various, and powerful:

- Unsustainable house price increases encouraged unsustainable lending to home owners and an **economic bubble** that politicians fear they cannot prick without electoral damage.
- Rhetoric which targets politically weak groups (like disabled people) are popular with key electoral groups, offering them both a **scapegoat** and a fictional sense of superiority.
- Lobbying by **powerful private organisations**, like A4E and Unum, has ensured that public services and welfare rights can be sacrificed to organisations who also seem to be actively supporting every political party and think tank.
- The **passivity of the major charities**, who now all seem utterly dependent on maintaining a friendly relationship for reasons of money or status.
- The **weakness of disability advocacy**, which lacks clear leadership and which is divided into many groups and which has not yet found a way of connecting its concerns with wider community interests.

The fact that disabled people and the poor are not remotely responsible for the current crisis turns out to be irrelevant. The fact that disabled people and the poor are amongst the only groups who have not benefited from the artificially induced boom that preceded this crisis is also irrelevant. At times like this - when government needs a scapegoat - the only fact that is relevant is the fact that the poor and disabled people are poorly represented by the political system and can be easily stigmatised by our political leaders, by the media and by others interests.

So, it turns out that for us, all of our work to build 'ordinary homes' or to help people into 'socially valued roles' has not provided the protection we had hoped for. People with learning difficulties - and not just them - have remained a 'special group of people' who can now be selected for 'special treatment' from a system looking for someone to blame.

It seems to me that we have been complacently blind to the real forces that are working to undermine the status and rights of people with learning difficulties.

This complacency is certainly natural. When human beings think things are going well then they are not prone to look around for problems or for information or ideas that may be too disturbing.

For the last twenty years I think the debate within the enclosed world of community services for people with learning disabilities has been divided between those who largely have said:

- a.** We've got people out of the institution, and now we must keep people safe, well, provide good care and avoid abuse, **or**
- b.** The real job is still ahead of us, we must get people into real homes, real jobs, real communities and real relationships.

But while this is an important debate, it turns out that something much more worrying has been happening. Increasing numbers of people now seem to believe some or all of the following falsehoods:

- The only way of having value is to earn lots of money or be famous
- It is a tragedy to have a disability or to have someone with a disability in your family
- It is okay to use genetic engineering, abortion or euthanasia to get rid of disabled people
- Human rights are a luxury that we can no longer afford
- Moral values are all relative, life isn't sacred and some lives are just not worth living
- The welfare state is a burden on the taxpayer

Some of these beliefs are more prominent than others and few, and only the most extreme modern-day eugenicist, might publicly articulate every belief. But these lies form an increasingly significant part of the zeitgeist, and we can no longer afford to ignore them. It is against the backdrop of these lies that many of the current government's policies make most sense.

Those of us who have been working with people with learning difficulties and their families over the past few decades bear a special responsibility here. We are not directly to blame for these lies and the growing injustice of government policy; but we are the ones who have earned our livings by trying to help people. If we have left people exposed to public scorn and abuse then we have a responsibility to do something about this problem.

5. WITH OUR EYES OPEN

We must challenge ourselves to move forward with our eyes open. We need to abandon the special jargon and the formulaic approaches to change. Instead we need to get more practical, more political and more in tune with our times and the interests of ordinary people.

We cannot afford to remain naively optimistic or resort to empty conversations within our own narrow world. It is clear that the primary threats facing people with learning difficulties come from outside our special world.

If we have vision we will both identify those threats and opportunities for positive change that exist in the wider world. Here are some more positive thoughts about our future strategy:

- **Get organised** - There still remain many individuals, families and organisations who understand what people's rights mean and what a fair society demands. It makes sense to pull together the strongest possible alliance and to help define a future direction from those values. There has always been a danger in expecting government to set the agenda, to provide the funding and to define the necessary regulations. For disabled people in the UK we can now see that, when the wind changes and government becomes actively hostile to the rights of disabled people, we cannot afford to be without leadership.
- **Build alliances** - Very few of the barrier to citizenship facing people with learning difficulties are specific to people with learning difficulties. People with mental health problems and prisoners also share experiences of unfair imprisonment. Older people and people with physical disabilities also share experiences of paternalistic segregation and isolation. All citizens, especially women and families, who are living in poverty share the same experience of a stigmatising and poverty-inducing benefits system.
- **Be practical** - If we are serious about change then we need to be focused on the practical business of making good things happen. Too often organisations, including charities, have been far too competitive and unwilling to share their own learning. Instead we have become lazily dependent on consultants and government - expecting ideas to come from 'on high'. But real change and innovation only comes from getting stuck in, solving problems and learning from your peers.

- **Be political** - Policies don't change on their own. Policies change because of the political process. Political champions must be identified, ideas must be presented, data and case studies shared and pressure brought to bear. In particular, being political also means talking in terms that ordinary people understand. Jargon locks us into our special world - we need to communicate with the bigger world outside.
- **Get real** - We can no longer afford to talk in code and just keep talking to each other. We are championing powerful and positive ideas which would benefit many people, not just people with learning difficulties and their families. But we must frame these solutions in ordinary language and in terms that resonate with everyone. We must stop being afraid to talk about relationships, love and human kindness. We must unapologetically assert basic human rights - not as special pleading - but as relevant to all of us.

Developing a 21st century vision begins with honesty, facing the truth of our situation. But if we want to move onto developing a positive vision of the future ahead then this must be appeal to the citizen in all of us.

CONCLUSION

I just want to conclude with five very practical observations.

1. One simple step might be to clarify our objectives and measure our success. For members of H&SA it seems possible to develop quite a robust set of measures of progress towards real citizenship that connect with wider society's understanding and which demonstrate the contribution that people with learning difficulties make to society (and the barriers that society creates to contribution):

- levels of home owners
- levels of employment
- levels of volunteering
- levels of income and tax paid
- levels of employment produced
- levels of business set up

2. Service providers, local authorities and advocacy organisations (the organisations that constitute H&SA) remain a powerful source of moral authority in our society. If we organise ourselves properly **people will listen**. Moreover, these organisations still have resources and, unless people want to be subject to on-going cuts, then they also have every incentive to get organised and to defend the rights of people with learning difficulties.

3. If H&SA are successful in organising themselves and their members I would encourage them to take seriously the imperative to support both **self-advocates and families**. The voices of both groups have been somewhat muted by the lack of People First England and the dominance of service provider organisations that do not seem to properly represent the interests and voices of either families or individuals. The current work of citizen and quality checkers offers a powerful alternative to current systems of regulation.

4. Quite rightly H&SA members are also passionate about closing the new institutions in which people are incarcerated. I think this is quite properly a priority for H&SA. However I think it is important to ensure that this work includes more significant efforts to share good practice in providing **more flexible and effective support** to people who will not fit into standardised solutions. The challenge is not just to close the new institutions but also to modernise and improve existing services.

5. Finally I would encourage H&SA and its membership to support the work of the [Campaign for a Fair Society](#) to challenge cuts in social care, income security, housing rights and the rhetoric which support these cuts. The Campaign offers an important bridge to working with others in the disability movement and it provides, not just an analysis of the problem, but a description of the kind of **fair society** we should all be working towards.

AUTHOR'S NOTE

In this paper I use the term 'people with learning difficulties' (the term preferred by the UK self-advocacy movement) to refer to people who are elsewhere referred to as people with learning, intellectual, developmental or cognitive disabilities (or impairments). I also use the term 'disabled people' in preference to the internationally more common term 'people with disabilities' - again to respect the primarily UK audience of this paper.

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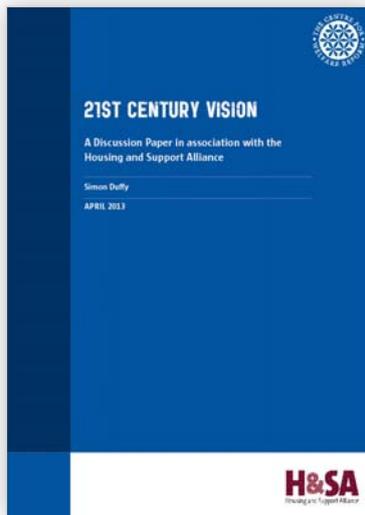
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